



QUALITY OF LIFE AND SOCIAL SUPPORT AMONG PARENTS OF ADOLESCENCE WITH THALASSEMIA

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ABSTRACT

Thalassemia major causes sufferers to experience severe anemia. This can impact parents' daily lives as a caregiver of adolescents with thalassemia and makes social support important. Objective: This study aims to identify the relationship between social support and quality of life in parents who have adolescent children with thalassemia major at dr.Slamet Garut Regional Hospital. Method: A cross-sectional approach was applied in this study, which included 64 parents of adolescents with thalassemia major (10-18 years old) who were selected using a consecutive sampling technique. Quality of life values were assessed using the World Health Organization Quality of Life Brief Version (WHOQoL-BREF) and social support was scored using the Multidimensional Scale Of Perceived Social Support (MSPSS). The WHOQoL-BREF is a valid ($r=0.390-0.798$) and reliable ($\alpha=0.941$) instrument, as is the MSPSS questionnaire ($\alpha=0.920$). Spearman correlation test was used for bivariate analysis. Results: There 52 respondents (81.2%) had high social support and 61 respondents (95.3%) with a good quality of life. The results of the correlation analysis revealed a significant relationship that exists between social support and parents' quality of life with a correlation coefficient = 0.447 ($p<0.05$). Conclusions: Therefore, this research concluded that there is a relationship between social support and quality of life among parents of adolescents with thalassemia major at dr.Slamet Garut Regional Hospital. High social support can improve parents's quality of life as a caregiver.

Keywords: adolescents; parents; quality of life; social support; thalassemia

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INTRODUCTION

Thalassemia is a genetic disease that is transmitted from thalassemia gene-carrying parents (Haq et al., 2023). In recent years, there has been an increasing trend of thalassemia cases in Indonesia. In 2019, west Java became the province with the highest number of thalassemia cases in Indonesia with 3.200 cases (Widiantoro et al., 2019). Garut Regency is an area with high thalassemia cases. There were 300 patients with thalassemia major who underwent routine blood transfusions at dr.Slamet Garut Regional Hospital in 2023. Patients who received blood transfusions were predominantly children and adolescents. Adolescents with thalassemia major need attention because they experience several problems both physically and psychologically, such as slow growth, fatigue, weakness, and pain (Mariani et al., 2020).

Some adolescents also experience yellowish skin (jaundice), abnormal facial bones (face cooley), distended abdomen, and even causing severe anemia conditions that have caused them to have regular blood transfusions.

Parents are the primary caregivers for children who are undergoing health care, allowing them to experience problems such as economic and communication problems, worrying about their children's future, and other psychological disorders (Rokhaidah & Herlina, 2018). These problems can reduce the quality of life among parents, so they need psychosocial support (Pruthi, 2020). Some factors may affect caregivers' quality of life in some previous studies, such as age and gender, spiritual aspects, marital status, education level, health status, social support, family support, caregiver burden, and acceptance of the patient. However, social support is an external aspect that can be received directly by caregivers such as parents. Social support can come from friends, family, or close people who lead to feelings of comfort, care, self-esteem, or direct assistance (Sarafino & Smith, 2014). Social support received by parents as caregivers can provide positive encouragement and hope in the childcare process. Lack of social support for caregivers can impact adapting difficulty to their problems, increasing caregiver burden, and decreasing physical and psychological conditions (Amylia & Surjaningrum, 2014).

Preliminary studies in the thalassemia room of RSUD dr.Slamet garut to 5 parents of thalassemia children found that 4 of them were dissatisfied with their lives lately and sometimes felt tired when caring for their children. However, 4 respondents said that they had received support from their husbands, families, friends, and nurses. The parents felt that this support was meaningful to their lives. The nurse in the room also said that the patient's parents always try to accept their child's condition and continue to live well. The support that parents need at this time is motivation and direct assistance such as blood donation. Caregivers have several problems that can ultimately affect their lives. Therefore, the quality of life for parents caring for children diagnosed with health problems needs to focus on, especially children with thalassemia major because the treatment lasts a lifetime. In addition, caregivers need social support while caring for children to reduce the impact that can be caused while caring for children. Therefore, the researcher aims to conduct an objective to find out the relationship between social support and quality of life in parents having adolescent children with thalassemia major at dr.Slamet Garut Regional Hospital.

METHOD

This research is a descriptive study that will illustrate the aspects studied with a quantitative approach so the data is obtained in the form of numbers. The statistical technique used to assess the relationship between variables in this study is a correlational technique with a cross-sectional approach. The subjects in this research are parents having adolescent children (10-18 years old) with thalassemia major and underwent blood transfusion at dr.Slamet Garut Regional Hospital. sampling technique is consecutive with a population calculation of 77 people and tolerance level is 5%. This study has obtained ethical permission from the Ethics Committee of 'Aisyiyah University Bandung with an ethics permit letter numbered 727/KEP.01/UNISA-BANDUNG/II/2024. The Indonesian version of the WHOQoL-BREF questionnaire was applied to find out the level of quality of life in the parents. The statement items cover the dimensions of physical health, psychology, social relationships, and the environment with 26 statements. Each item contains a value category from 1 to 5. Previous research has tested the instrument on 30 respondents at Talun health center. The calculated r value was 0.390-0.798 while the reliability test value was 0.941, which was declared valid and reliable. Social support was measured using the MSPSS questionnaire which contains 12

statements including family, friend, and special person support. This questionnaire has been translated into Indonesian by Betty & Rahayu (2023). The instrument test was conducted by Mauna (2022) on 42 parents of children with special needs and the items were declared valid and the reliability result was 0.893. Data analysis consisted of univariate and bivariate. Univariate analysis is calculated by calculating the frequency distribution of categorical data while bivariate analysis used Spearman's rank correlation to test the relationship between variables.

RESULTS

The respondents in this study collected 64 parents who have adolescents with thalassemia major in dr.Slamet Garut Regional Hospital, Data in this research was collected on March 1-22, 2024 and reached the minimum sample (n=64).

Table 1.
Respondent characteristics (n= 64)

Respondent characteristics	f	%
Age		
19-44 years old	35	54,7
45-59 tears old	29	45,3
Gender		
Male	19	29,7
Female	45	70,3
Marital state		
Married	59	92,2
Divorced	1	1,6
Widowed	4	6,3
Education level		
Primary school graduate	23	35,9
Junior school graduate	19	29,7
High school graduate	17	26,6
Diploma or university graduate	5	7,8
Occupation		
Unemployment	40	62,5
Labor	7	10,9
Farmer/rancher/entrepreneur	6	9,4
Private employees/ Employees	8	12,5
Military/police/civil servants	3	4,7
Income level		
Below the regional minimum wage	43	67,2
Equals regional minimum wage	17	26,6
Above the regional minimum wage	4	6,3
Number of thalassemic children		
1 child	49	76,6
2 children	12	18,8
More than 2 children	3	4,7
Chronic illness		
None	55	85,9
Heart disease (history of heart attack)	1	1,6
Hypertension	3	4,7
Other	5	7,8

Table 1 shows that the majority of respondents were in the age group of 19-44 years (54.7%), female (70.3%) and married (92.2%). Respondents were average elementary school graduates (35.9%). In line with respondents who were large as mothers of patients, the highest of respondents did not work (62.5%). Based on family income, more respondents were categorized as below the minimum wage (67.2%). However, the majority of respondents (76.6%) only had

one child with a thalassemia major in the family. Physically, most of the parents (85.9%) did not have chronic diseases.

Table 2.
Frequency distribution of social support (n= 64)

Social support	f	%
High	52	81,2
Medium	11	17,2
Low	1	1,6

Data on the level of social support received by parents of thalassemia adolescents in Table 2 concluded that more respondents (81.2%) had high social support.

Table 3.
Frequency distribution of quality of life domains (n= 64)

Quality of life domains	f	%
Physical health factors		
Poor	7	10,9
Good	57	89,1
Psychological factors		
Poor	5	7,8
Good	59	92,2
Social relationship factors		
Poor	4	6,3
Good	60	93,8
Environmental factors		
Poor	5	7,8
Good	59	92,2

Table 4.
Frequency distribution of quality of life (n= 64)

Social support	f	%
Poor	3	4,7
Good	61	95,3

Tabel 3 and 4 above, almost all respondents (95.3%) have a good quality of life. When viewed by domain, the social support factor has the highest good category (93.8%).

Table 5.
Correlation test of social support and quality of life (n= 64)

		Social support	Quality of life
Spearman's rho	Social support	Correlation Coefficient	1,000
		Sig. (2-tailed)	,447
		N	64
	Quality of life	Correlation Coefficient	,447
		Sig. (2-tailed)	,000
		N	64

The results of the Spearman rank correlation test in Table 5 obtained a significance value (2-tailed) of 0, which means that there is a significant relationship between the variables of social support and the quality of life of parents of thalassemia teenagers. The correlation coefficient in the test is 0.447, which means that the level of correlation strength is categorized as the moderately strong category.

DISCUSSION

Social Support

Based on the interpretation of the research results, 52 parents (81.2%) received social support in the high category, 11 parents (17.2%) received social support in the medium category, and one respondent (1.6%) received low social support. These results aligned with previous research conducted on mothers as their children's caregivers where most respondents received high social support from the five social support factors (Karima et al., 2023). However, these results are different from other studies conducted on parents of patients with thalassemia major where most of the caregivers in their study did not receive social support, causing negative impacts in the form of social problems and depressive symptoms in parents (Ginanjar et al., 2021). The difference in research results can be influenced by several things, one of which is the marital status of adolescent parents in this study, as many as 59 respondents (92.2%) were married. The harmonic relationships between parents can create an attitude of mutual assistance in providing support in caring for children with thalassemia (Nurvinanda et al., 2019). Support from spouses is one form of social support that is important for parents as caregivers. All parents of adolescents with thalassemia at dr.Slamet Garut Regional Hospital is a rural community where they have intimate relationships. In contradiction to urban communities that prioritize rational benefits in a relationship so that the relationships created are less in-depth and social interactions are less familiar (Daldjoeni, 1992). Familiar relationships in the community can be a form of social support from friends. In addition, social support can also come from family. High levels of social support in families who have thalassemia children can reduce stress levels and create positive psychological responses (Nurvinanda et al., 2019).

Social support is defined as a type of assistance provided by someone to others and comes from social relationships (Widiantoro et al., 2019). Social support consists of emotional, appreciative, instrumental, and informational aspects that can be sourced from family, friends, or special people (Fadhilah, 2016). Parents as caregivers need support during the care process. The support needed can come from family, friends, and partners. Factors that influence social support in respondents in this study are the relationship with a partner (marital status) and the domicile or residence of parents where both factors support parents to have higher social support.

Quality of Life

The outcome of the measurement of parents' quality of life showed that 61 respondents (95.3%) had a good quality of life and 3 respondents (4.7%) had a poor quality of life. Based on the domain, social relationships obtained the highest results from 60 respondents (93.8%) classified as good. These results are similar to the results of research conducted on parents of adolescents with thalassemia that the majority of respondents had a quality of life classified as good and quite good (Fitriliani et al., 2020). This good quality of life will have a positive effect on the treatment process and parental compliance in treating children with thalassemia (Fitriliani et al., 2020). However, these results are inversely proportional to research in a study conducted on caregivers of children with thalassemia major. In this study, more respondents had a poor quality of life, causing stress and tension for parents (Biswas, B. et al., 2020). Another study also obtained results where most of the quality of life of parents of pediatric thalassemia patients was low and dissatisfied in all four quality of life domains (Pruthi, 2020). The difference results is affected by several other factors. The contributing variables that allowed the respondents in the study to have a better quality of life were their age and the number of children with thalassemia. A study explains that younger caregivers can care for children better so they do not get more pressure and disturb their psychology (Shamsaei et al.,

2015). Another factor is that as many as 76.6% of parents in this study only have 1 child with thalassemia major in the family. This allows parents to have a better quality of life because the larger number of children with thalassemia will lead to a reduction in the parents' quality of life due to the higher number of treatment processes (Bakthavatchalam, 2019).

Other variables that were also recognized were the physical health and economical condition of the respondents. Almost all parents (85.9%) had no health problems, which has a positive impact and satisfaction on the care process, thus improving their quality of life (Biswas, B. et al., 2020). In addition, economic status affects the quality of life among parents towards meeting childcare needs (Fitriliani et al., 2020). The majority of parents (67.2%) had an income below the minimum wage. However, all of them received health assistance funds. A study showed a positive effect on patients who received health assistance funds and those who did not on the quality of life of the patient's family (Gratia et al., 2020). Quality of life refers to an individual's view of their own life, includes life goals and expectations, and is related to a person's ability to obtain a life according to the expected standards. Results of measuring the quality of life in parents using the WHOQoL-BREF questionnaire mostly are classified as good. Some factors can increase the quality of life among parents in this study, namely age, economic conditions or family income, physical health, and the number of children with thalassemia.

The correlation between social support and Quality of Life

This study found a correlation between the research variables, namely social support and the quality of life of parents of adolescents with thalassemia major. Regarding the significance value, the result is 0.00, which means there is a significant relationship between these variables. However, the category of the correlation level of the two variables is included in the moderately strong category. Other studies have also tested these variables, for example on parents of autistic children who obtained high social support and quality of life results, and stated that there was a significant relationship between the two variables (Kuru & Piyal, 2018). Another research done in Egypt found a relationship in social support with quality of life on mother who have thalassemia children (Ibrahim et al., 2021). Social support provided by the family and gratitude are assessed to affect the quality of life among parents as caregivers, whereas the higher the social support and gratefulness, the higher the quality of life in parents (Ikhwanisifa et al., 2024). Other studies have also found a strong relationship between social support, caregiver burden, and quality of life among parents. The higher the parents' social support, the higher the quality of life and the lower the caregiver burden (Yildirim et al., 2022). This statement is the same as with the relationship between social support and the quality of life of parents as caregiver of thalassemia children. In agreement with the previous statement, the lack of support received by caregivers is also a contributor to their low quality of life (Biswas, B. et al., 2020). Social support is also related to caregiver adaptation, so it is important to strengthen the quality of support that is given to patient caregivers (Melguizo-Garín et al., 2021).

The same outcomes were found in a study conducted on caregivers of children with developmental disabilities where the high level of social support obtained was associated with improved caregiver quality of life (da Costa et al., 2020). In another study conducted on 200 families of cancer patients in Bangkok, it was found that social support received by families significantly predicted their quality of life. It also correlated with strong relationships between caregivers, cancer patients, other family members, and friends (Warapornmongkholkul et al., 2018). Through these results, it can be summarized that the support from the family also has a positive influence and impact on the caregiver's life. High social support provides more

chances for caregivers to be able to share insecurity, uncertainty, and daily activities with others so they can improve adaptability, self-esteem, health status, and social attitudes and reduce negative symptoms in psychological aspects (Erbay et al., 2021). A person's perceived satisfaction with social support also affects the domains of quality of life, especially in the domain of social relationships. In line with this statement, parents in this study received the highest result 93.8% in the social relationship domain. This proves that good social support for thalassemia caregivers can create good social relationships in the quality of life aspect.

Quality of life is an analysis of a person's strength to obtain a normal life, it relates to the individual's perception of the purpose of hope, standards, and attention to his life. Meanwhile, social support is defined as a way of helping individuals receive from their social ties, and this creates a meaningful impact on the individual. The quality of life caregivers can be affected by their age, conditions of health, income, knowledge level, social and family support, and enjoyment in caring for children (A. Y. M. Putra et al., 2020). In line with earlier statements, caregiver quality of life is influenced by family economic conditions, social support, physically health and acceptance of the child (Suharta, 2020). This study gains the conclusion that quality of life and social support have a positive relationship in parents who become caregivers. When there is an increase in social support, the quality of life also increases and the opposite is true. The positive relevance between the two variables can be a step for caregivers to improve their quality of life. A step that can be performed by supporting the caregiver, for example by giving education or information related to the child's condition (Setiyawati et al., 2022). Research limitations that need to be considered for the development of further studies are the limited sample so that it does not reflect a wider variation to describe the experience of parents in caring for adolescents with thalassemia major, less consideration of other variables that may have an effect on quality of life of parents, such as spiritual aspects, caregiver burden, and positive caregiving experience and the use of non-experimental methods.

CONCLUSION

This study summarizes that there was a moderately strong relation on social support and quality of life among parents of adolescents with thalassemia major at dr.Slamet Garut Regional Hospital. The existence of a relationship between social support and the quality of life of parents as caregivers can be a concern to improve or maintain the quality of life of parents of adolescents with thalassemia major. Suggestions for future research can explore other factors that may affect the quality of life of caregivers in thalassemia children, such as positive caregiving experience, caregiver burden, or spirituality conditions.

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